1979

The Huston Committee Report

on the prevention of mental retardation and developmental disability in Saskatchewan

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101-07512/

COMMITTEE ON

THE PREVENTION OF MENTAL RETARDATION

AND

DEVELOPMENTAL DISABILITY

IN

SASKATCHEWAN

Saskatoon, Saskatchewan
January 22, 1979

Hon. H. Rolfes
Minister of Social Services
2240 Albert Street
Regina, Saskatchewan
S4P 2Y3

Dear Sir:

We are pleased to present the final report of the Committee on the Prevention of Mental Retardation and Developmental Disability in Saskatchewan.

It was a pleasure for us to serve on this Committee and we appreciated the opportunity of consulting with personnel throughout the province on this important topic. We have enjoyed our work and hope that our recommendations will contribute to the improved prevention of mental retardation and developmental disability in Saskatchewan.

We would like to acknowledge the excellent support and cooperation we received from government personnel and experts who gave so freely of their time and resources when approached by the Committee.

Peter Huston, Chairman
Jack Funk
Brian Hanson
Hugh Grocott
Witold Zaleski
Margaret Norum
Wilmer Bates

Claire Medak
Frank Dornstauder
Bob Livingston
Chesley Wells

Vince Matthews

V. T. Matthews

SUMMARY OF RECOMMENDATIONS

Preamble:

The majority of recommendations relate to medical and biological technology and the means of applying this to the whole population because the possibilities for effective intervention at the technical level have increased enormously in the last two decades. The prevention of developmental disability is, however, as much a social as a medical problem because poverty, excessive dependency and poor environmental conditions are likely to have more impact on the problems than would advances in technology. Although some desirable changes are taking place at the present time, others are not; social changes are long term and complex because effective alleviation of poverty, ignorance and damaging life styles is dependent on economic progress as well as general, social and cultural change. Nevertheless, we recommend the promotion of fundamental social change through preventive measures, adequate nutrition and housing and healthy life styles would ensure that a significantly greater number of children are born free from developmental defects.

Recommendations:

1. That the Government of Saskatchewan give priority to the primary prevention of mental retardation and developmental disorders by all means possible, with the objective of substantially reducing the incidence of developmental disability over the next decade.

2. That the Government of Saskatchewan, in cooperation with University

Departments, professional education programs and voluntary agencies, actively promote the professional and technical upgrading of services in antenatal, obstetric and neonatal care to the high degree of competence necessary to reduce perinatal mortality and morbidity to the lowest possible level.

3. That the Government of Saskatchewan promote and support efforts by government agencies, professional education, and voluntary agency activity to improve the state of public knowledge about human reproduction and emphasize the role of responsible parenthood as a major influence in the reduction of mental retardation and developmental handicap.

4. That the Government of Saskatchewan explore the possibility of developing improved information about the epidemiology of mental retardation and developmental disability, as a guide to ongoing programs.

5. That the Government of Saskatchewan, through it's Department of Health:

i) Promote high quality programs of antenatal care to all citizens, including those who are the administrative responsibility of the Federal Government.

ii) Promote high quality intensive perinatal care programs in Regina and Saskatoon, with adequate staff and suitable supporting transport for sick infants and their mothers.

iii) Promote an integrated program of genetic counselling and advice to all members of the population who need it.

iv) Use the resources of its health promotion branch to promote the

principles of responsible parenthood, and specifically to take measures to discourage the birth of children to women under the age of 20 or over the age of 35.

6. That the Government of Saskatchewan, through its Department of Social Services, explore realistic support services in the home which will reduce the hazards of pregnancy in disadvantageous conditions, including the use of homemaker services, financial support, and other methods found effective in preventing developmental disability.

7. That the Department of Education of the Government of Saskatchewan, through its Departments of Special Education and Continuing Education, develop programs to develop information for parents and future parents concerning measures which can reduce the toll of developmental handicap, particularly those measures concerned with life style, and endeavor to influence public thinking in a manner which will lead to a major reduction in developmental handicap.

TERMS OF REFERENCE OF THE COMMITTEE ON THE PREVENTION OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITY IN SASKATCHEWAN

A Committee composed of individuals who are active and responsible in public affairs, including government departments, voluntary agencies and professional associations, were appointed by the Minister of Social Services and convened by representatives of the Core Services, in 1976 to:

1. Discuss the various aspects of mental retardation and other developmental disorders, with additional input provided by experts in appropriate fields.
2. Outline present procedures and practices that are available to accommodate the above.
3. To identify additional resource needs.
4. To prepare a report to assist those concerned with public policy in developing programs which will reduce mental retardation in the future.

MEMBERS OF THE

COMMITTEE ON

THE PREVENTION OF MENTAL RETARDATION

AND

DEVELOPMENTAL DISABILITY

IN

SASKATCHEWAN

Jack Funk	- Executive Director, Core Services Administration Government of Saskatchewan
Claire Medak	- Regional Coordinator, Core Services Government of Saskatchewan
Brian Hanson	- North Regional Coordinator, Core Services Government of Saskatchewan
Frank Dornstauder	- Program Consultant, Planning and Evaluation Division Department of Social Services Government of Saskatchewan
Hugh Grocott	- Director, Child Health Division Department of Health Government of Saskatchewan
Bob Livingston	- Chief, Special Education Department of Education Government of Saskatchewan
Witold Zaleski	- Medical Director Alvin Buckwold Centre Saskatoon, Saskatchewan
Vincent L. Matthews	- Professor and Head Department of Social and Preventive Medicine Saskatoon, Saskatchewan
Margaret Norum	- Program Coordinator Continuing Nursing and Medical Education Saskatoon
Chesley Wells	- Research and Evaluation Branch Department of Continuing Education Regina, Saskatchewan

Wilmer Bates	- Executive Director, Saskatchewan Coordinating Council on Social Planning Regina, Saskatchewan
Arthur Huston	- Acting Clinical Director Valley View Centre, Core Services, Mental Retardation Division Moose Jaw

Substitutes

Janet Swenarchuk	- Department of Social Services, representing Frank Dornstauder
Shirley Rawlyk	- Department of Special Education representing Bob Livingston
Daryl Sullivan	- Saskatchewan Coordinating Council on Social Planning replacing Mr. Wilmer Bates
Beth Trotter	- Department of Social Services representing Frank Dornstauder
Norma Fulton	- Continuing Nursing Education representing Margaret Norum
Vera Spencer	- Department of Health representing Dr. Hugh Grocott

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Brief prepared by:	- Bette Fox Medical Secretary Valley View Centre, Core Services Mental Retardation Division Moose Jaw
Editorial Services:	- Margaret Pearse Sarich Medical Editor College of Medicine University of Saskatchewan Saskatoon

FORWARD

Because of its lifelong nature, mental retardation is one of the most significant causes of human misfortune suffered by individuals and members of their families. Many types of mental retardation and other developmental disabilities are now preventable, due to the large and rapidly increasing body of knowledge about the causes and ways to prevent or relieve these causes.

The children of the future have a right to be well born. There is a growing body of expert opinion that preventive measures for such distressing conditions should be applied as soon as possible and that individuals, agencies and governments may be increasingly called to account for failure to act whenever prevention is possible.

Mental retardation is also a source of great public and individual expense. These expenses may take the form of lifelong institutional care, or the provision of very special services in the community. To these costs, one can now add the costs of loss of a productive life span which might have been preserved by proper preventive measures. An authority on the economics of mental retardation has estimated that each affected individual represents a life-cost of around one million dollars in the present United States economy. The situation is likely to be very similar in the Canadian setting.

For these reasons, the Committee was appointed by the Minister of Social Services to study the various aspects of preventing mental retardation and developmental disorders, and to compile information designed to assist those concerned with public policy in developing

programs which will reduce mental retardation in the future.

Although each of the eleven committee meetings held were centered around a specific topic, there was a noticeable tendency to return to important themes. Several of these themes were concerned with knowledge and attitudes of the public in general rather than with technicalities, and most members of the committee believe that increased public education and understanding is a major factor in reducing developmental disability. They felt that there is a lack of practical knowledge of this subject even among educated people, to the point that for most committee members, the meetings were of mutual education.

Responsible parenthood is also a powerful force in prevention while "life styles" is an important causative factor in developmental disability, thus a change in life styles is important form of prevention.

The Committee also stresses the importance of applying preventable technical knowledge, especially in antenatal and perinatal care, as well as more effective utilization of services already in place, such as public health nursing, social work, and special education of younger children.

Consideration about the problem of preventing mental retardation and developmental disability appears to be as advanced in Canada as in any part of the world, and is one of the major contemporary themes among the medical profession, those concerned with social issues, and members of the public exposed to the problem. Committees that have been and are currently active include:

1. Committee of the Canadian Association of Mental Retardation: The main theme of this committee has been preventable biomedical conditions and significant reports have been made on causative factors of rubella and lead poisoning. One of our committee members is also a member of this committee as were two of the guest participants.

2. The Committee of the Saskatchewan Association of Mental Retardation (S.A.M.R.) began soon after our own committee was formed and includes some of our guest participants and one of our members. This committee has developed the concept of a Prevention Institute as a major contribution to the reduction of developmental disability, possibly using funds from the Kinsmen Foundation for the Handicapped, and the Provincial Government.

A combined planning meeting of members of the Committee of the S.A.M.R. and of the Government was held to study ways of implementing the development of a Saskatchewan Institute for the Prevention of Handicaps. Our Committee also participated in a combined meeting with the S.A.M.R.

These developments indicate that Saskatchewan is as actively engaged in working toward prevention of mental retardation and developmental disability as any other area in the North American Continent. The current task is to relate these considerations to practical means of implementation.

In the prevention of mental retardation, developmental disability and brain damage which has its origin in avoidable biomedical hazards, our Committee felt a certain sense of urgency to promote the best possible programs to improve matters. The interest of the unborn generation might,

in principle, appear to receive high priority in the thinking and action of mature adults. In practice, the evidence of history is that this is not the case. Historically, children's hospitals and services for children have usually developed later than service for adults. In recent years, the principle of intensive care has been established for many types of catastrophic or severe illness. Examples of this are coronary care units, intensive care units for the post operative patient, and special units for terminal kidney disease, brain injury and severe burns. In nearly every example quoted, programs for adults suffering from these disabilities were established well in advance of the development of perinatal intensive care for the small or sick newborn child. This trend should surely be reversed, and the promotion of life, vigor, and normal brain function in the next generation should be one of the major priorities in health programs at the therapeutic or preventive level.

CHAPTER 1: THE NATURE OF THE PROBLEM

I. Developmental Disability: The use of this term, used throughout the paper, requires explanation because the Committee was formed to consider the prevention of mental retardation.

Developmental disability is a recent term adopted when it became necessary to consider all aspects of human development together. The term, does however, defy exact definition. It includes mental retardation and a wide range of other problems which cause great human distress and public expense. The term is used to designate conditions which arise as a result of hereditary disease, disorders in antenatal life or the process of birth, perinatal illnesses, disease, injury or intoxication occurring in the first three or four years of life, and producing severe or permanent abnormality of development. Among the developmental disabilities at the present time are:

1.) Most causes of crippling disease in children. These are Cerebral Palsy; Myelomeningocele; the muscular dystrophies and atrophies; congenital amputation; limb defects and skeletal disorders; acquired causes such as head injury, amputation; acquired diseases such as rheumatoid arthritis.

2.) Most causes of sensory handicap in children, including blindness, major visual handicaps, deafness and major hearing disability.

3.) A significant proportion of all cases of epilepsy.

4.) An unknown but probably large proportion of those problems included under a variety of labels such as "learning disability".

5.) Congential abnormalities as a whole, including many not associated with mental retardation.

For a detailed description of these disabilities, see Appendix C, Definitions.

II. Mental Retardation:

This term is not an exact description of any group of human beings, but usually is defined as that segment of the population whose intelligence quotient (I.Q.) falls two standard deviations below the norm, or below 70. The norm for the population as a whole is 100, and the most numbers of a total population described as normal fall within the range of 85 to 115. Those above 115 are usually described as being of superior intelligence, those in the range of 70 to 85 as slow learners. The use of the I.Q. as a means of categorizing people is, however, open to serious objections because it is not a fixed measurement but can be modified to some degree by experience and education. It is also believed that the criteria used in forming the I.Q. are too narrow to be universally applicable. Nevertheless, the traditional use of the I.Q. provides a basis for discussion which helps to indicate the size and scope of the problem.

Three per cent of the total population are believed to have an I.Q. below 70. The general term mental retardation includes a group of citizens with a wide range of disabilities whose understanding requires an individual approach to each situation, rather than a categorical attitude to the problem as a whole. Some have a mental handicap of such severity that it is obvious at the first glance. Others are so close to the normal population in capacity that their difficulties can only be discerned by special testing. Some have mental handicaps

combined with physical disability, such as cerebral palsy, blindness or deafness.

Some sub-division of this population is helpful in understanding. Appendix B, gives an indication of the size of the problem related to the population as a whole, and the ways it has been classified in the past and at the present time. The old terminology of moron, imbecile and idiot, with its insulting connotations, is no longer used to describe individuals with problems of mental retardation or developmental disability.

In Saskatchewan, the institutional population of retarded individuals is around 1,000 people, with 770 in Valley View Centre in Moose Jaw, and about 230 in North Park Centre, Prince Albert. The institutions provide residence for a substantial proportion of the severely and profoundly retarded individuals, and some of those categorized as trainable. The majority of those regarded as educable, and many in the trainable category are accommodated in various community programs and special educational centres.

CHAPTER 2: PREVENTION OF MENTAL RETARDATION AND DEVELOPMENTAL HANDICAPS

I. The Nature of Prevention:

Prevention of any disorder can be divided into three major categories:

1. Primary Prevention: Because appropriate action is taken, the condition does not occur at all. An example of this is a fall in the incidence of Downs Syndrome because older women decide not to have children.

A major problem in primary prevention is that causative condition is often not diagnosed. For example, at the present time, there is little comment about the large number of young adults who do not suffer disability because of tuberculosis, yet this condition was one of the most common causes of illness in early adult life only a generation ago. Similarly, in the type of cerebral palsy known as kinicterus, due to rhesus iso-immunisation, has almost disappeared. The children at risk for this type of cerebral palsy who have been correctly treated, and have become normal members of the community should be remembered when the issue of primary prevention is considered. In the future, there are likely to be many more examples of primary prevention in which effective intervention has produced an individual of normal social function.

2. Secondary Prevention: The condition occurs, but effective action corrects the disorder. Examples are phenylketonuria (P.K.U.) or thyroid deficiency (Cretinism), where recognition in very early infancy and appropriate medical treatment prevents retardation from occurring.

Secondary prevention is easier to discern, because it depends upon the diagnosis of the condition.

3. Tertiary Prevention: This condition exists but is ameliorated by intensive therapeutic programming without actually being altered. For example, a child born with definite retardation achieves reasonable

educational and social competence by good early programming. There is considerable overlap between tertiary prevention and good care of the retarded.

Tertiary prevention is also easier to note because it is concerned with management of the established condition at the earliest possible stage.

The fact that secondary and tertiary prevention are more noticeable should not allow attention to be diverted from the importance of primary prevention.

II. Knowledge:

At the present time, it is hardly possible to pick up a major journal or medical practice, pediatrics, obstetrics or family practice journal, without finding articles on various aspects on prevention of mental retardation and developmental handicaps. This enormous flood of information indicates the subject has become an actively growing part of medical and biological science, and even those most deeply involved in various aspects of the problem find it exceedingly difficult to maintain contact with literature on the subject. For this reason, a brief digest of literature cited in Appendix D provides information about the various important aspects of prevention, without attempting to make a comprehensive report of the subject.

Contemporary advances in knowledge which are leading to increased possibilities of prevention of developmental handicap appear to come from three main areas of human endeavor.

1. Fundamental medical and biological science: major advances have been made in this area within the past three decades, and even greater

developments can be expected in the future. Discoveries such as an accurate count of the number of human chromosomes, and the relationship of the common condition of Downs Syndrome to a chromosomal abnormality have been of recent occurrence. Increasingly accurate knowledge of cell structure and biochemical processes are having profound and far-reaching effects on medical practice applied to human reproduction and early development.

2. Epidemiology: This is the study of the circumstances in which disease processes arise. Observations such as the high proportion of Downs Syndrome children born to older women, or the relationship between low income and antenatal abnormalities, have profound implications for future planning.

3. Studies of Early Development: Intensive studies of the early development of infants and children have indicated that alterations of environmental factors and child raising practices may have profound effects on development, even in the presence of major abnormality.

CHAPTER 3: PREVENTIVE MEASURES: WHAT CAN BE DONE TO PREVENT MENTAL RETARDATION AND DEVELOPMENTAL DISABILITY

Our current ability to prevent mental retardation and developmental disabilities is related to the degree to which the processes causing the disability are understood and can be controlled. Knowledge is still fragmentary in many cases where there is often no clear understanding of the process involved or reliable methods to alter these processes. Opportunities to prevent disability increase, however, as advances in medical and biological science lead to greater understanding.

Simple cause and effect relationships are not always found in developmental disabilities. Multiple factors can contribute and probably do so more often than not. Cultural and environmental factors can profoundly modify the outcome of child bearing, and the environmental and cultural setting in which medical and biological problems arise, may have as much influence on the outcome as the original problem itself.

The cause and alleviation of mental retardation and developmental disability are considered under four main headings, which often overlap.

I. Hereditary disorders and Chromosome abnormalities.

II. Disorders of Antenatal Life, the Birth Process and the Perinatal Period.

III. Postnatal Disorders.

IV. Social, Cultural and Environmental Conditions.

I. HEREDITARY DISORDERS AND CHROMOSOME ABNORMALITIES:

1. Hereditary Disorders.

Although a comparatively small proportion of cases of affected individuals have a clear history of any hereditary disorders, this element in mental retardation and other developmental disorders is probably over estimated by the public. Some authorities believe that between 10 and 20% of all cases of mental retardation have an important hereditary element in their causation, while hereditary factors may play an important part in other cases with multiple causation. Some hereditary conditions could cause disastrous disability. An example is Tay-Sachs disease, in which an infant who is normal at birth becomes epileptic, blind and profoundly mentally defective in a matter of a few years, invariably dying. This rare condition can sometimes now be diagnosed before birth. On the other hand, some hereditary disorders are amenable to treatment. An example is phenylketonuria, in which there is an hereditary enzyme deficiency which can be corrected by appropriate diet, provided the diagnosis is made sufficiently early in the antenatal period.

Counselling is often required to make maximum use of presently available knowledge. This usually involves a systematic discussion of the situation between prospective parents and the physician or geneticist, the construction of a family pedigree, and the use of special tests such as examination of blood specimens from the parents, amniocentesis, and the use of diagnostic ultrasound. While there is a tendency to think of the technical aspects being of primary importance,

the most fundamental advance in our knowledge is presently made by the ability of a skilled genetic counsellor to analyse the situation correctly and provide advice to prospective parents that help them make difficult decisions.

Genetic counselling can be applied over a wide aspect of medical practice. In the prevention of mental retardation and developmental disability, its uses are most likely found in the following areas:

a) Families with a definite history of disability in recurrent generations;

b) families in whom first degree relatives have a child with an abnormality. It is also justifiable to extend genetic counselling to include families in whom second degree relatives have produced a family member with an abnormality;

c) families who have had a bad reproductive experience. This could include the birth of a defective child, a stillbirth, or difficult previous pregnancy. In this category, genetic counselling is likely to be basically of a reassuring nature.

d) families having children in situations known to be associated with abnormalities, such as high maternal age.

2. Chromosome Abnormalities.

Although not all chromosome abnormalities are hereditary, their analysis and management require the same methods as those used in genetic counselling. A prime example is Down's Syndrome, formally called mongolism, and described in Appendix E.

Amniocentesis, a technique frequently used in the analysis of genetic chromosomal conditions, is discussed in the section titled Antenatal Care.

Although genetic counselling services are gradually becoming generally available, a meticulous accuracy demanded in such work, particularly at the laboratory level, makes rapid expansion of the services difficult. Programs concerned with genetic counselling would probably be overwhelmed if all families who could benefit from this service were to present themselves.

Medical services in technically advanced countries need to consider the problems of an expansion in genetic counselling services so that they can be available to all members of the public who need them because routine use of genetic services would have an impact on the incidence of major mental retardation and developmental disability. It's most immediate result might be a reduction in the number of cases of Down's Syndrome born to a woman over 35.

Extended programs of genetic counselling would have two other advantages which could become significant over the years.

a) reassurance of parents who have reproductive problems not caused by genetic abnormality. This role of reassurance could also be extended to problems of hereditary or chromosomal nature. For example, among women over 40 carrying a fetus, there is an increased chance that the fetus will be a case of Down's Syndrome. In this situation, some parents may be faced with the distressing and difficult decision as to whether or not to terminate the pregnancy; others may gain

great benefit from reassurance that they do not carry a fetus with this particular abnormality.

b) Expansion of genetic services may also prove important in future management of a variety of disease. For example, it may become possible to identify and even initiate preventive measures in individuals with tendencies toward diabetes, arthritis, emphysema, cancer or psychiatric illnesses.

Neural tube deficits can cause very severe mental retardation as well as crippling disorders, which are described in Appendix F. Recent diagnostic developments provide hopeful signs that a general prenatal screening test for this condition may be available in the near future.

II. ANTENATAL DISORDERS, THE BIRTH PROCESS AND PERINATAL PROBLEMS:

The influence of antenatal disorders in the causation of mental retardation and other disabilities has been underestimated, however, increased knowledge about the management of pregnancy, birth and the newborn period make prevention a most hopeful aspect at the present time.

1. Antenatal Care.

There has been a significant decrease in the maternal death rate in all countries with technically advanced medical services, to the point where death associated with giving birth to children is now a rare phenomenon, and when it does occur, is usually associated with some serious maternal disease. Traditionally, the family physician or obstetrician has always given life or death of the mother priority,

but advances in the past three decades are such that it is now possible, without prejudicing the life or health of the mother, to give virtually equal weight to the needs of the fetus. The ability to take mother and child through difficulties in the reproductive process and preserve the health and function of both has progressed in a parallel manner, much of which is a reflection of improved technology.

The organization of this technology so that it will be available to those most needing it is a major problem. The two aspects of technology in antenatal care that have received much attention and deserve comment are ultrasound and amniocentesis.

a) ultrasound: in the past, x-rays were sometimes used to outline the fetus in the mother's body, and valuable information was obtained, however, x-ray exposure of a small fetus to "full body" radiation, is a damaging environmental influence in much the same way as might apply to an adult exposed to an atomic explosion. The use of ultrasound technology, which has become a regular requirement of obstetrical referral centres, has provided a safe means of monitoring fetal development. This technique makes it possible to determine the position of an unborn child, make informed judgements about major abnormalities, and to visualize the placenta, as a major assistance in other diagnostic procedures such as amniocentesis.

b) amniocentesis: this is a procedure in which the fluid surrounding the developing fetus is taken from the pregnant uterus and analyzed in various ways. At present, the problems surrounding

amniocentesis are considerable because this process cannot be performed before the thirteenth or fourteenth week of pregnancy, and many of the decisions based on the analysis need to be made before the sixteenth week. Nevertheless, amniocentesis does provide an opportunity to diagnose and monitor, and while many conditions are susceptible to diagnosis, in actual practice, a comparatively small number of conditions are regularly diagnosed by this procedure. Among these are:

i) Down's Syndrome; by culture of feto cells from the fluid, which show the condition of trisomy of chromosome 21.

ii) Neural tube deficits; by showing the elevation of alpha feto protein.

iii) The sex of the fetus, which may be indicative in conditions such as muscular dystrophy, where the condition is sex linked.

Amniocentesis can also be valuable in later pregnancy to determine the maturity of the fetal lung and to assist in making direct decisions about the time to deliver a child. It is also of value in cases of iso-immunization disorder (Rhesus factor). The technique of manipulation within the uterus has advanced to the point where some fetuses suffering from severe iso-immunization disorder have received intraperitoneal transfusions of blood, with preservation of life and brain function.

Another development which is likely to expand in the future is the procedure of fetoscopy, in which the fiberoptic technique makes it possible to see inside body cavities, and is applied to the pregnant uterus, and the developing child is visually inspected.

The use of such advanced technology may appear esoteric and unrelated

to the management of normal pregnancy in healthy women. While this is, to some extent true, the art and science of the new obstetrics demands these methods of selecting individuals who require the application of new technology to preserve life and function in the affected fetus. Hence, the modern approach to the organization of knowledge about individual mothers-to-be is of fundamental importance. By recording the appropriate data about a specific pregnancy, it is possible to produce relatively accurate forecasts about the degree of risk to which an individual mother and child are exposed. While the low risk mother is imminently suitable for delivery in normal circumstances, backed by sufficient facilities to deal with unexpected problems, the high risk mother can have her delivery and perinatal care arranged in centres equipped to produce optimum results in the management of mother and child. Although this tendency is being followed to an increasing extent, it requires an organized approach of regional development of maternal and perinatal health services. Recommendations for the type of facility necessary in different levels of care have been made by the Committee on Perinatal Health of the March of Dimes, and provide guidelines for the establishment of services which are accepted by many authorities. An example of the type of documentation recommended for pregnant woman at the present time is shown in Appendix G.

c) Antenatal disorders in the stages of pregnancy: Pregnancy may conveniently be divided into three stages or trimesters.

i) The first trimester: the first three months are the stage when the major body plan is being laid down, and while this common-

place biological miracle is usually achieved without any problems, it is quite possible for disaster to happen from causes which may have little or no effect upon the woman carrying the developing fetus. Examples of these as well as active efforts presently made to prevent abnormalities arising from disorders of this type are:

- women should not have abdominal x-rays requiring substantial x-ray exposure in the second half of their menstrual cycle if there is the slightest possibility of pregnancy.

- the use of drugs of any sort in pregnancy is now curtailed to a degree although there is room for an improvement. Considerable medical discretion must be used in the management of necessary drug treatment of early pregnancy in which the needs of the mother must be balanced against the needs of the fetus. Casual use of medication in pregnancy is now strongly discouraged and the tendency is to reduce medications to those drugs essential for preservation of life and health.

- infections in early pregnancy may be trivial to the mother but very damaging to the fetus. While it is believed this may occasionally occur with a great many infections, there is one specific example which is extremely important, because total prevention is theoretically possible. This is the condition of rubella, comparatively trivial to the mother but with the capacity of producing disastrous damage to the fetus in the early stages of development. The issue of rubella is set out in Appendix H.

- alcohol and nicotine are poisonous substances known to cause

irreparable damage to some unborn children, and may have a harmful effect to some extent to all fetuses. Cigarette smoking is associated with low birth weight infants, and cerebral palsy in a significant proportion of mothers. The fetal alcohol syndrome is now a well recognized condition, related to heavy maternal ingestion of alcohol; the possibility exists that even moderate alcohol consumption or social drinking may be associated with some degree of abnormality in the unborn child. There is ample evidence now to suggest that all expectant mothers should neither drink alcohol nor smoke cigarettes.

ii) Second trimester: during the second three months, the general body plan of the unborn child has been laid down, including much of the early development of the brain. On the other hand, rapid development which has a profound influence on intellectual development is taking place in the supporting cells of the brain. During this period, satisfactory nutrition is a fundamental importance. In some parts of the world, where calorie and protein malnutrition is deficient, much subtle damage to the developing fetus may be taking place. In recent years, studies in many parts of the world have shown the importance of that nutritional deficiency in early life can have on the reduction of some forms of mental retardation. The true extent of this problem may still be underestimated in the world as a whole. The evidence suggests that adequate protein intake is of fundamental importance to brain growth during the middle and later months of pregnancy and during the first three years of life; if there is protein deficiency, the development of an adequate network of nerve cells and of supporting nerve structures

may be seriously deficient. Inadequate nutrition in early and prenatal life may play a part in producing a widespread degree of deficient brain growth in whole populations. There is the possibility that major intellectual upgrading of such populations can take place if the nutritional problems can be corrected.

The extent to which such conditions are actually found in Saskatchewan may be a matter of controversy. Frank nutritional deficiency does not appear to be a serious and obvious problem in the population as a whole, however, among the profoundly retarded, there is an undue proportion of native Canadian children who sometimes live in conditions similar to developing countries where nutritional deficiencies occur.

The problem of nutritional deficiencies is far from simple. Income supplements may have a part to play in some circumstances but does not necessarily ensure that pregnant women and young children actually receive the nutrition which they require. Despite this, the state of nutrition deficiency and means of its correction are an important long term subject for study and active.

iii) Third trimester: the main disorders of the last three months of pregnancy are toxemia and preterm birth.

Toxemia of pregnancy has a relatively higher association with cerebral palsy and some types of mental retardation. It is also a condition which is usually susceptible to medical management, provided that it is identified. This condition and other conditions giving rise to problems in later pregnancy were found most frequently in women going through their pregnancy without adequate medical supervision.

Prematurity is one of the major associations with cerebral palsy and mental retardation. The prevention of prematurity is, to some extent, related to the management of late pregnancy, and occurs more frequently when there has been inadequate supervision of a woman's condition. The problems of prematurity, dysmaturity, and preterm birth are discussed under the heading of perinatal care.

2. The Birth Process.

The process of birth can be associated with damage to the newborn, the most significant of which is due to a lack of oxygen. This factor has probably been somewhat over estimated in comparison with the importance of antenatal factors. When some of the antenatal indicators of difficulties are present it is now possible to monitor the birth process enabling intervention on behalf of the fetus, thus preventing damage to the child's brain. In the majority of births, this is not necessary and the problem is to develop criteria for deciding when such close supervision is required. The potential of such methods for preventing brain damage is so great that there are authorities who feel that all births should be monitored. At the present time, resources for this are not available; as well, there are serious objections to developing such a highly technical approach to child birth.

What does appear to be required is for physicians and nurses caring for mothers-to-be to develop the capacity to make adequate decisions in advance of difficult circumstances. This is not always

possible, but can be done in an increasing number of cases. Indicators of impending difficulty include the presence of maternal ill health, particularly that due to diabetes or chronic renal disease. Toxemia of pregnancy indicates that a child may require skilled resuscitation. The presence of twins can be anticipated, and their delivery in appropriate circumstances arranged. Many criteria exist for deciding where a birth should take place. Active decisions must be made in all cases concerning the appropriate place for any particular birth, and for the transport of the mother-to-be and her unborn child to the appropriate place in good time.

a) Neonatal care: The care of the recently born infant is one of the areas in which the most spectacular advances have been made. Studies of the physiology of breathing, the importance of maintaining acid-base balance and blood sugar, as well as the need to preserve the brain from such catastrophies as shortage of oxygen or excess of bilirubin have all led to a remarkable transformation in the fate of many newborn infants. These advances have been most noticeable in management of the small premature child.

Pre-term birth has two main aspects:

i) Prematurity, or low birth rate, and short gestation. A typical example is the "seven months baby". Such infants are the product of a gestation which, for a variety of reasons, is cut short. In the past many such children suffered from cerebral palsy. With appropriate management it is now possible to compensate for the loss of the interuterine environment, and maintain these infants in good condition, with full brain

development, by meeting their nutritional and other needs. Wherever the full technology is applied to this problem there is a spectacular fall in the premature death rate, and the noticeable reduction in the incidence of brain damage.

ii) Dysmaturity, fetal malnutrition or the "small for dates" baby. In this condition, infants are born with low birth weight following a gestation of normal length. There are probably a great many causes for this condition, originating with development problems in utero. A significant proportion of such infants have brain damage or other congenital abnormalities, and our capacity to improve this situation is limited at present. Nevertheless important advances are being made in the antenatal diagnosis of this condition, with subsequent intervention at appropriate points in the development of "small for dates" children. The capacity to manage small infants has improved so much that there are times when Caesarian section is used to remove such an infant from a uterus no longer capable of providing adequate support, and maintaining the child on artificial support until a viable condition is reached. As the disabilities related to true prematurity are prevented, the problems of dysmaturity will be revealed to an increasing extent. Their prevention is, however, likely to require advances in antenatal care.

3. <u>The Perinatal Period</u>.

<u>Perinatal screening</u>: Two major disorders associated with mental retardation are so amenable to treatment that all infants are now screened for them by means of a test to determine whether or not the

condition is present. Examples are phenylketonuria (P.K.U.) and hypothyroidism (Cretinism). In many instances, both these conditions can be prevented if appropriate treatment is given as soon as possible after birth.

The principle of screening whole populations is one of importance, and may have wider applications in the future. While the process may appear to be expensive it is a very economical procedure if retardation is prevented in even a few individuals. While the incidence of phenylketonuria in a population is around 1 per 12 - 15 thousand births, a screening program in Saskatchewan is likely to reveal only one affected child per year. Nevertheless, the costs of $36,000.00 to test 15,000 new born children in the province each year, are comparatively low compared to the cost of even a few years of maintenance of an untreated case of phenylketonuria in an institution. In the case of thyroid deficiency in infancy, the cost benefit is even greater, as universal testing is likely to reveal one example of the condition for every four or five thousand births.

The whole area of antenatal care, supervision during the birth process and perinatal care is likely to be the aspect of mental retardation which can give most immediate benefits at the present time. To summarize some of the important factors in the prevention of prematurity and high risk pregnancy the points described in Appendix I, have been taken from a standard text book on the management of high risk pregnancy and intensive care.

4. Postnatal Causes of Mental Retardation and Developmental Disability.

Possibly one-fifth of all mental retardation is due to damage of the brain of infants after the first month and before the end of the third year of life.

The causes of such damage are numerous, some such causes are manifestations of conditions existing either before birth or in the perinatal period, and some of these declare themselves as severe epilepsy in the first year of life. A proportion of these catastrophies may well be averted by improved antenatal and perinatal care.

Infections in infancy are important cause of serious brain damage. These may be due to meningitis, for which effective antibiotic therapy is usually available if the condition is recognized, the early recognition of treatable brain infections is an important component of the care of sick children, and catastrophies are most likely to occur when, for any reason, children are not under medical supervision when they are ill.

Virus infections of the brain, or encephalitis can cause catastrophic brain damage. Many such infections are not preventable at the present time, but some are caused by insect bites and can be prevented when epidemics occur, by the protection of new born infants from being bitten by insects.

Shortage of oxygen from any cause can produce catastrophic brain damage. This may occur in near-drowning, suffocation, or as a catastrophe during anesthesia. Some of these catastrophies could be avoided if a competent knowledge of first aid were wide spread amongst the general population.

Head injury plays a significant part in the causation of brain damage. Serious injury of the brain in road accidents occurs among infants, and

can be reduced by proper infant sitting in vehicles. Proper sitting restraints for infants are still used comparatively rarely compared to the adult population, and the development of an effective infant car seat at a price excessible to all the population, will contribute to the reduction of mental retardation.

A significant cause of head injury is child battering. Whether it is more common than in former years, or more usually recognized, may be controversial. The Criteria for recognizing the possibility of its occurrence, and for assisting families in which it has occurred, are improving. Suspicion of the possibility is important in preventing this aspect of mental retardation.

Poisoning from various chemicals and medications is a possible cause of catastrophic brain damage, and is one cause of acquired mental retardation. The protection of children from such hazards is still defective.

An important potential cause of mental retardation is lead poisoning. When this occurs it is usually found in infants chewing lead paint used on old buildings, or it has been described following the inhalation of fumes from burning lead batteries. Automobile fumes in areas of heavy atmospheric pollution has also been suggested as a possible cause. Blood levels higher than normal have been described amongst children in urban ghetto areas associated with atmospheric pollution.

Other heavy metals, particularly mercury, have been implicated in brain damage. Although mercury poisoning can certainly produce very

severe loss of brain function its contribution to mental retardation is not known.

The extent to which environmental hazards such as toxic poisons from agricultural sprays, pesticides etc.,damage infant brains to the point of producing mental retardation is not known, but serious anxiety has been caused by the possible relationship between Reye's Syndrome, and sprays used for the spruce bud-worm. Whether there is a cause and effect relationship is uncertain, but this example emphasizes that the protection of small children from toxic chemicals is likely to prevent some examples of mental retardation.

CHAPTER 4: SOCIAL, ENVIRONMENTAL AND CULTURAL COMPONENTS

Disorders of structure or abnormalities in the chemical function of the brain appear to cause mental retardation to such a degree that it sometimes appears that all retardation must have such a basis. This, however, is not the whole truth. Retardation, and the degree exhibited, appears to be decided to a considerable extent by the social and environmental circumstances in which the child is born and spends the early years of life. Poor children are more likely to be retarded than children born to more prosperous parents. Even more influential than the economic background is the quality of child care given, and children born into homes in which loving and capable parents provide stimulation and support exhibit fewer of the signs of retardation then do children reared in situations where good care and stimulation are not provided. Some authorities believe that as much as 10% of all the children who become catergorized as retarded have no structural or chemical abnormality in their brains but have become deficient in response to environmental deprivation. Such children can sometimes be improved to a more normal level of ability by changing the environment.

It is probable that virtually all mentally retarded and developmentally handicapped children can be helped by attention to their special social and educational needs early in life, even if their problem is associated with disorders of brain structure. Individualized programs applied early in life have improved the function and learning ability of many children with conditions such as Down's Syndrome, cerebral palsy, or multiple handicap. The need to correct disorders of vision and hearing,

or to compensate for their loss as early as possible in infancy, is becoming more widely understood. In the past many developmentally handicapped children were placed in institutions. This often added an element of social and cultural deprivation to their problems which reduced many children's ability to function to a very low level. Programs are now developing, such as the Portage early childhood development curriculum, in which systematic educational stimulation is provided for mentally and physically handicapped children from an early age. Such programs, administered by parents and parent substitutes in the home or in developmental centres, and supervised by psychologists and educators trained in early childhood stimulation, are proving to be superior to any type of institutional care in promoting the development of handicapped children. They are also proving acceptable to the great majority of parents, and are economical compared to the alternative of institutional care.

I. Life Styles and Prevention:

It is known that smoking by a pregnant woman can adversely effect the development of her unborn child, and that such children are more likely than others to have cerebral palsy. Recent years have seen the identification of a "fetal alcohol syndrome" in which there is a characteristic appearance and constellation of abnormalities, including mental retardation, in infants born to women who are heavy drinkers of alcohol. Some drugs given for their therapeutic effects have been associated with abnormalities in the unborn child, the most spectacular example being the limb deficiencies following maternal

ingestion of Thalidomide. Women who have consumed marijuana or LSD are believed to have a greater chance to giving rise to abnormal infants, although this has never been proved. Infants born to mothers on heavy doses of heroin may be themselves be affected. The potentially disastrous effects of deficiencies in diet, particularly of proteins, have been shown in antenatal and post-natal nutrition of children. The association between many of the complications of child bearing and poverty have been confirmed many times over.

All this indicates that many aspects of the problem of preventing mental retardation and developmental disability are amenable to social action. Some of this action might well be related to income supplementation in special cases, to ensure that the developing child has a fair share of desirable nutrition and care at the time when it is needed most.

Other aspects of the problem require the understanding and involvement of prospective parents, and more effort could be made in this area to inform the public of some of the risks related to life styles, and of the opportunities that can arise by the avoidance of such risks. The information concerning smoking is now receiving attention from many young parents, and the dangers of heavy drinking are becoming much better understood. Nevertheless, the idea that the fate of one's unborn children may to be some extent in one's own hands is still not as widely known as it should be, and provides an opportunity for specialized health education programs, and education programs in general, to attempt to affect the thinking and actions of adolescents and young adults who wish to become good parents.

An important issue not widely known to the general public is the overall statistical effect of the age of the mother at the birth of a child. Children born to mothers under the age of 20 or over the age of 40 have a significantly higher liability of having some type of an abnormality than do children born to women between the ages of 20 and 40. If the desirable age range of a mother for giving birth is narrowed to between 22 and 36 the issue becomes even clearer. Over the age of 35 there appear to be greater biological hazards, particularly in an increased liability to such chromosome abnormalities as Downs Syndrome. In giving birth under the age of 18 the incidence of prematurity and toxemia arises. Pregnancy in early adolescence shows a higher association with various developmental abnormalities. In later adolescence this is not so marked, but probably the majority of adolescent pregnancies take place in conditions of social disadvantage in which the effect of poor care, ill-health, and lack of means accumulate to provide a set of disadvantageous circumstances for any child coming into the world. In considering the prevention of mental retardation and developmental handicap there are strong reasons for discouraging pregnancy in conditions of disadvantage. In an age in which conception is becoming, or could become, more and more a matter of voluntary choice, there is evidence that the manner in which the choice is made can influence the outcome to a degree greater than has previously been known. Parents who are in good health, in adequate economic circumstances, and who want the child, have a significantly higher chance of achieving their family without problems than do parents

having families under various types of handicap. The importance of adequate family planning in improving the health of the next generation may be very great, and the need for this to be understood by the population as a whole needs emphasis.

Major problems arise among groups of the population who are not in close contact with sources of knowledge. Social groups who have limited means, a high dependancy ratio, and lack of rapport with the dominant culture are unlikely to be affected by such arguments unless special efforts are made to reach them. Nevertheless, the desire to have healthy mentally sound children is universal. Needs must be developed to help all segments of the population to achieve this as far as possible.

II. Technical Problems and Ethical Issues:

In a pluralistic society, in which many points of view have validity, it is important that considerations of human reproduction and its management are sensitive to all shades of opinion. There is a paradox that at a time when it is possible to intervene more and more affectively in the defence of an unborn child, this is also a time in which termination of pregnancy is being done more often than ever before. Many parents will have the most profound reservations about permitting termination of pregnancy even of a fetus which is destined to be handicapped, and physicians who have assisted parents of handicapped children know the heights of dedication and sacrifice that they are capable of in the care of their damaged young. On the other hand, some of the objections to termination of pregnancy when severe handicap exists appear to come

from individuals who have little idea of the extent of the problems that some of the handicapped can present. This is an issue that is likely to be encountered more and more frequently in the next generation. It will be necessary for prospective parents facing these issues to have access to full, sympathetic and competent advice about the problems, the limitations of knowledge, and the means to carry out any course of action which they elect to follow.

To see the issue of termination of pregnancy in some proportion the following comments may be relevant.

1. Termination of pregnancy for proven fetal abnormality is likely to occur in a statistically rather small number of pregnancies compared to the total number terminated in the interest of the life and health of the mother at the present time.

2. Spontaneous termination of pregnancy (miscarriage) is a relevently common natural phenomenon, and there is some evidence that a substantial proportion of miscarriages are the result of genetic and chromosomal abnormalities. The extent to which this is so is still far from understood, as the technical problems of examining the products of a miscarriage on a large scale are considerable.

III. The Paradox:

In reviewing the possibilities in contemporary reproductive medicine there is, in the minds of many, an element of nightmare. A

pregnancy punctuated by amniocentesis, a labour monitored, and a infant starting life in the sterile atmosphere of an incubator are components of a technical scenario which is anathema to many members of the public. At the other extreme is seen the pregnancy arising out of a good life style of sound nutrition, a natural childbirth, and the harmonious development of a breast fed infant well bonded with the parents. The point of a few of those who advocate "natural childbirth", and the post-natal care which is associated with it is one which deserves a great deal of respect, and could be an important part of a movement toward responsible parenthood. Difficulties arise however because there appear to be no absolutely reliable criteria to ensure safe and comfortable childbirth by "natural" methods. In producing the next generation, time and chance come to all men and women to some extent, and it is a reasonable statistical expectation that one birth in 200 will be associated with some unforeseen abnormality. What appears to be needed is an extensive dialogue between members of the professions and members of the public, particularly prospective parents, so that the benefits and limitations of various courses of action can be examined. There is no necessary conflict between the technically excellent neonatal nursery which can preserve the developing brains of some of the smallest infants, and the practice of natural childbirth by healthy, well educated parents intent on raising healthy children.

CHAPTER 5: THE SASKATCHEWAN SCENE

I. How Developmental Disability and Mental Retardation Can be Reduced

a) Considerable advances in the Prevention of Developmental Disability have been made in Saskatchewan in recent years. For example, brain damage due to erythroblastosis has been virtually eliminated, while the perinatal mortality rate has declined nearly 40 percent in the past eight years. On the other hand it is only a few years since the perinatal mortality rate was one of the highest in Canada, and the present rate is higher than that achieved in many other technically advanced societies. The development of necessary aids to diagnosis, such as ultrasound and amniocentesis, have lagged behind other programs in Canada, while arrangements for effective regionalization of antenatal and perinatal services, and of the transport facilities necessary, are still quite deficient. The expert technology needed is not lacking, but the organizational pattern which enables it to be applied to all members of the population who need it has not been fully developed.

In developing an effective approach to the prevention of developmental disability new patterns of professional activity and public participation will be required. While physicians and other health workers will develop effective technologies, there will be a need for active participation by a wide range of health workers and members of the public, and probably the development of new patterns of professional activity. The effective use of community health workers such as field nurses, social workers, teachers, and homemakers, all effectively equipped with current knowledge of

possibilities of prevention, is likely to have as much impact as the development of high level technology in hospitals and among medical and nursing personnel. To be effective this, new knowledge must be applied to those who need help most, and to reach these members of the population is likely to require effective and coordinated activity by health workers in close contact with the population concerned.

b) Hereditary Disorders and Chromosome Abnormalities.

Competent programs for genetic counselling and diagnosis of chromosome abnormalities are available in the University of Saskatchewan in Saskatoon. Services in Regina require development to the same level at least.

Regional consultative services need to be developed using both regional field staff and consultant counsellors from the University of Saskatchewan in Saskatoon and from comparable consultant services developing in Regina. With proper training and adequate numbers regional field staff can play an important part in preliminary screening, and providing follow up services.

As public demand increases, step by step development of appropriate laboratory facilities are required. One must remember, however, that the training of staff for such services takes time.

Economic provisions such as transport and lodging will be required to enable the disadvantaged members of the population to take advantage of the service.

c) Antenatal Care, The Birth Process and Perinatal Problems.

i) Antenatal Care:

Antenatal medicine has made advances in Saskatchewan in recent years comparable to that made elsewhere in advanced countries. The use of "at-risk" evaluation forms is another means of anticipating problems is much more prevalent then in times past, and is likely that a good deal of the credit for this change should go to the Programs of Continuing Medical and Nursing Education, who have repeatedly presented the issue of antenatal and perinatal care to members of the medical and nursing professions. Antenatal at-risk evaluation is now a regular feature of the nursing care rendered by nurses employed by the federal government in Indian and Northern Health Services, and more and more potential problems are referred for specialized care. Regionalization of obstetric service is showing developments, although there are gaps in the organization and in the knowledge of some members of the professions concerned. Financial support for obstetrical services in areas where this lack of obstetrical care remains should be withdrawn.

Certain groups in the population are still not adequately covered by antenatal services. Noticeable amongst these are native canadian women living on reservations or in urban ghettos. Many of these are very young women and some are alienated from the prevailing culture. There is evidence that this group produces a significant proportion of the stillbirths, perinatal problems, and handicapped children. Improvements are taking place in assisting this group in having healthy children, but

real advances are likely to require not only technical improvements, but the development of rapport and social contact to a degree that has not been achieved in the past. The cooperation of leaders in the native Canadian community, particularly among the mature women, may be a very significant element in making changes.

The potentially damaging effect of alcohol and tobacco on the unborn child are still insufficiently well known to the population as a whole, perhaps particularly to those whose cultural background does not lead them to read very much. The desirability of reducing or eliminating consumption of alcohol and tobacco should be presented to those who require the knowledge, but an approach recommending prohibitions is likely to have limited effect. The combination of reduced alcohol and tobacco consumption with promotion of positive nutrition, and perhaps also of the means of requiring such nutrition, is likely to be more effective. Guidelines for adequate nutrition in pregnancy are well established, and are indicated in the Canada Nutrition Guide. The cost of good nutrition however is considerable, and a new implementation of an adequate nutritional policy may well have financial implications for some hard pressed members of the population.

A neglected aspect of the prenatal care in the past has been prenatal education of parents. There appears to be a wide spread and developing public demand for information on this subject. In a Saskatchewan city as many of 45% of all pregnant women have attended classes operated by a health department. Significant in this program was the higher

attendance by potential fathers as well as mothers. Such programs may have a significant impact in informing members of the public about the possibilities of preventing developmental disability.

ii) Birth Process:

The vast majority of births in Saskatchewan take place in hospital, and this is likely to continue, although there is an element in the population which is seeking more opportunity for births at home. In the present state of organization of services, it would be difficult to strongly recommend home birth as a regular part of reproductive care, but the gradual development of supporting services to enable it to happen in association with low risk natural childbirth could be compatible with the aim of reducing developmental handicap through adequate type of organization, although it is unlikely that such organization will develop rapidly.

In the conduct of normal birth in hospital, the essential feature at the present time is the ability to anticipate problems. This is developed comparatively well, but exceptions occur which give rise to avoidable catastrophe. The anticipatory monitoring of pregnancy, particular in relation to such problems as dysmaturity, is not universally practiced, and children born in inadequate circumstances are still hurried to perinatal nurseries in poor condition. Not all such problems can be avoided, but with adequate consideration many of them can be prevented to a far great degree than is generally realized.

The actual conduct of birth in low risk pregnancies is probably as adequate in Saskatchewan as anywhere else in North America. Even the low risk birth is subject to a certain number of unavoidable and unexpected

difficulties, and a major advance in the prevention of mental retardation and brain damage is made if all births are conducted in circumstances in which anoxia in the newborn child can be instantly relieved. This requires a certain amount of technology in the handling of instruments etc., and in the management of the child, and is unlikely to be developed in circumstances in which childbirth is a very rare event. The actual number of births which a hospital or a physician should attend to maintain competence is still a matter of some controversy, but it is probably true to say that any hospital not conducting 20 births a year should not have an obstetrical service.

iii) Perinatal Care:

The perinatal unit which has been active in Saskatoon for several years has played a major part in recent reduction in perinatal death rate. The size and staff available in Saskatoon are probably adequate for the area served which is Northern and Central Saskatchewan, including a considerable proportion of the far North. Problems exist even in this effective unit, and it is important to realize that units accepting responsibility for all the cases who need the service must have adequate staff. It seems probable that two physicians specializing in perinatology are needed for each centre with a specialized unit doing this demanding work.

The unit opened in Regina last year is still in the developmental stage. It is important to promote the development of this unit to adequate standards as quickly as possible, and this is an essential part of the development of pediatric services in the regeneration program of the

Regina General Hospital. Much remains to be done in Regina to make it a centre of excellence in providing perinatal care of a standard available in some other centres in Canada.

Regionalization and rationalization of programs for specialized obstetrics and perinatal care present some problems in relation to hospital organization. In Regina there are two obstetric units, both of proven competence in the past. Nevertheless the provision of expensive monitoring apparatus and experienced staff probably require the amalgamation of these units and their location in one hospital. Many such organizational problems are not yet solved.

d) Transportation of the Neonate:

An important aspect of upgrading perinatal care is adequate transportation of infants to special centres. An effective transportation unit should be an extension of the perinatal program practices in the tertiary centre. This is achieved to some degree in the Saskatoon based program where every infant is transported in a suitable incubator, accompanied by a nurse clinician from the central perinatal unit. Incubators are at present in the process of upgrading. The Air Ambulance is mainly based in Saskatoon at the present time. Even journeys from Southern Saskatchewan to Regina are sometimes undertaken by aircraft based in Saskatoon.

Emergency transport of the acutely ill and injured, whether by air or by road, is still, in the opinion of many, inadequately developed. The use of the air ambulance in Saskatchewan was a pioneering effort in its time, and has certainly saved many lifes. The effective development

of transport to special centres does, however require a coordinated approach, using both air and surface, and the transport of the neonate is one aspect of this which deserves special consideration. It is important to emphasize that the best form of transport of developmental problem is achieved when the diagnosis of a potential problem is made before birth and unhurried transfer to a special centre is made as a deliberate choice rather than an urgent necessity.

e) Antenatal and Perinatal Screening:

The screening of newborn infants for P.K.U. has been established in Saskatchewan for many years, and appears to be as successful in preventing this rather rare condition in Saskatchewan as it is elsewhere. In the last year screening for hypothyroidism (Cretinism) has been added, with the hope that it will diagnose 3 or 4 affected infants per year. There are a variety of other, more rare conditions, which can be diagnosed by antenatal screening, and suggestions have been made that this type of screening should be added to the program already in existence. This is, in fact, an intricate problem, which is related to the size of population which can economically support an effective screening program. It has been suggested that the 6 million or so people in the four Western Provinces of Canada should have a single screening service able to cover all types of abnormality. Screening for conditions which cannot be effectively treated may be uneconomical and expensive. This is an issue likely to require a good deal of discussion over the next few years. The relative success and economy of programs for screening already operated in Saskatchewan

is worthy of note.

Antenatal screening has been a legal requirement for many years. The legal requirement is for testing the blood of prospective marriage partners for syphilis, and the retesting of all pregnant women is probably an effective means of controlling this condition. On the other hand the mandatory nature of the test has lead to the opportunity for the Province of Saskatchewan to test pre-marital bloods for Rubella antibodies, and it is found that perhaps 10% of women about to be married have a low level of antibodies to this virus infection which can damage the unborn child. The response to the recommendation that such women should be immunized, with the proviso that they are not already pregnant, has been less than was hoped when the program was instituted. At the present time, information about Rubella antibodies is transmitted to the physician who ordered the pre-marital blood test. While this information may well be a guide to action for a family physician in close contact with prospective parents in his practice, it very often happens that the pre-marital blood test is done as a rather nominal examination by a physician to whom the couple are not well known. In such circumstances a lack of follow up is understandable. Possibly the notification of the Public Health Department, and a cooperative effort between Public Health Programs and family physicians would be one way of reducing this completely avoidable hazard in child bearing. Direct information about such tests to the individuals concerned could also be considered as a means of promoting preventive action, but would probably require a better informed public to have wide impact.

Other screening programs may be developed in the future. Screening is a comparatively costly and complex way of identifying problems, and in the future criteria for screening selective elements of population are likely to be developed. Possibly there are other times of life in which screening might be effective. As part of an education program in late teenage years screening of girls in grade 12 for Rhesus Factor, Rubella antibodies, and other possibly hereditary traits might have something to contribute.

f) Prevention of Postnatal Causes:

Mental retardation occurring in a child whose antenatal development and birth have been normal is one of the most devastating of human tragedies. A great deal of medical care and an ordinary parental supervision of children is directed towards the prevention of such catastrophies. Nevertheless they occur. Their causation has so many factors that it is hard to recommend specific measures which are likely to be of universal application. There are however some factors more common in the Western provinces of Canada which deserve emphasis.

i) Viral encephalitis

Saskatchewan occasionally has epidemics of Western Equine encephalitis. Infants are peculiarly susceptable to this condition, and can suffer from brain damage of great severity. When this infection is prevalent, the careful protection of infants from insect bites can be an effective preventive measure.

ii) Accidental Poisoning

Accidental poisoning by drugs is a serious hazard to children between the ages of two and four. Although much reduced, it is still a serious danger, particularly from the commoner medications such as iron, tranquilizers and hypnotics. The enforcement of sensible practices covering the care of medication needs continual emphasis.

iii) Head Injury

Saskatchewan has laws concerning the use of seatbelts in vehicles, but the situation regarding small children is somewhat ambiguous. Programs exist for the rental of cheap effective car seats to parents at a very economical rates, and are much to be commended. The safety of play areas and other places where falls take place receives some attention. The relationship between substandard housing and severe injury to small children, including head injury, deserves more attention.

iv) Lead and Mercury Poisoning

There is little evidence to suggest that lead poisoning occurs amongst Saskatchewan children. Mercury poisoning has been suggested as a possible contributing factor to brain damage, but there is no evidence to support this. In Saskatchewan testing of blood samples for the poisonous heavy metals has not been widely applied, and may well be a subject for future study. Samples of mercury levels in

mothers and children from areas where there is a higher than normal incidence of mental retardation might have some value, either as an indicator of a possible problem, or as reassurance. The possibility of natural or industrial pollution of the environment exists from causes prevalent at the present time or perhaps developing in the future. Evidence that this contributes significantly to the problem of mental retardation at the present time is hard to find. There does appear to be a need for some continous surveyance of possible toxic factors in the environment, and perhaps the period revision of criteria for "safety levels".

v) Child Battering

This subject has received much attention in recent years, and criteria are being developed to identify it more often in Saskatchewan. Its well known association with young parents, broken homes, and alcoholism are all indicators as to where it may occur. The solution in Saskatchewan or anywhere else is likely to be part of a much broader and effective program of social prevention then is at present available.

CHAPTER 6: EARLY INTERVENTION PROGRAMS IN SASKATCHEWAN AS A FORM OF PREVENTION

Early intervention in the lives of children who either have or are likely to have mental retardation or developmental disability has not been widely practiced in the past, but has received more attention in Saskatchewan than in some other areas. An active and effective program has been conducted in the Saskatoon area, based upon the Alvin Buckwold Centre, with the help of skilled professionals in early childhood development. At the present time this program is very insecurally funded, and the pilot project is coming to an end. Most of those concerned with it would believe that it has justified itself by the improvement in the children who were involved in it, and in the confidence which such programs give to parents.

In primary and secondary prevention many of the issues are of a medical and biological nature, and many of the changes being made are carried out by health care professionals, or by members of the public, such as prospective parents, following discussion with health care workers. Tertiary prevention is, to a considerable degree, a different sort of activity. It is really an extension of education and psychological management into the very early stages of life, and most of it is actually carried out by individuals whose training is in the area of education, psychology and child management. Sometimes it is guided play. Sometimes it has a more formal educational content. Sometimes it is simply a matter of encouragement for parents to relate to a handicapped child and to take a part in a program of stimulation. It is a sustained program in

which personal relationships play as much part as technical procedures. Its results can best be appreciated by comparing children who have received such a program with similar children who have not. The experience in Saskatchewan so far would lead most people to believe that it is a program which should be extended to children who need it in all parts of the province as effectively as resources allow. Some programs are beginning to operate in different parts of the province other than the pilot project around Saskatoon, but it is still true that the majority of small children with major developmental handicaps are simply left in the care of their parents, and the capacity of the parents to assist them is often not seriously questioned. One of the rewarding aspects of providing a program of early intervention is that the great majority of parents respond to it in an exceedingly positive manner, and themselves become effective therapists and educators for their handicapped children.

In slightly older children alternatives to institutional care in Saskatchewan are now well established, and the network of special schools and developmental centres is available over much of the province. This form of early intervention is effective as far as it goes, but becomes a good deal more effective if it is applied to very young children.

1. Resources and Roles:

Measures which could be taken to reduce mental retardation and developmental disability in Saskatchewan involve activity by government

departments, voluntary agencies, and professional associations.

a) Government Departments

Government departments have considerable direct responsibility for issues concerned with health welfare and education, and perhaps even more indirect responsibility in the extent to which support is given to the promotion and financing of various programs. There is a need for sustained programs which are not excessively vulnerable to political change and variability in budget in activities designed to improve general health and welfare, and specifically to prevent mental retardation and developmental disability.

b) Saskatchewan Department of Health

Saskatchewan has a record which is a cause for satisfaction in in the promotion of health and the prevention of disease. Saskatchewan have taken a leading role in some aspects of prevention such as testing of pre-marital blood samples for susceptibility to infection with Rubella, in improved management and prevention of iso-immunization disorders (Rhesus Factor), the development of screening for phenylketonuria and hypothyroidism, and in the prevention of many forms of infection in early childhood. The activity of the Department of Health in the promotion of maternal and child health has been notable. Saskatchewan public health activity has been one of the most effective in the western world in programs requiring the occasional but effective contact with all members of the population.

The finding of a high perinatal mortality figure in Saskatchewan compared to other provinces a few years ago came as something of a shock

to those who had rightly taken pride in the Saskatchewan Public Health activity. Although this figure has shown improvement in recent years, it is still not as satisfactory as many feel it should be, while in some groups of the population the incidence of stillbirth, perinatal morbidity, and unwanted child bearing is disturbingly high. It seems probable that contemporary public health programs interested in the reduction of developmental handicap may have to find means for working intensively with certain segments of the population, rather than relying on programs which make the same sort of contact with the entire population.

c) The Community Nurse

The community nurse in Saskatchewan usually means a Public Health Nurse, but the term may also be used to include other nurses functioning outside the hospital setting but in the community, such as nurses working with the Victorian Order, Nurse Practicioners working in association with community physicians, and nurses working in home care situations under community boards.

Community nurses have played a major part in the development of public health services in Saskatchewan, and their activity in the control of infections and in the promotion of maternal and child health has been very significant in achieving at the present levels of mental and physical health in young children. A more intensive involvement in certain problem families and individuals by community nurses might well be a significant factor in reducing developmental handicap. The present nurse-to-population ratio would hardly permit

the type of involvement that would be required, as each community nurse is responsible for between 5,000 and 7,000 members of the population. In this respect the experience of a country somewhat comparable to Canada is significant. Finland, a large sparsely populated country with harsh climate, but with a well educated and technically competent population, has achieved one of the lowest perinatal mortality rates in the world. The Finnish authorities believe that this has been achieved largely because a very determined effort has been made to have at least nursing supervision of every pregnancy, with the direction of problem cases to the appropriate level of care. This has required a nurse to population ratio of not more than one to 2,700.

There is certainly room for improvement of the nurse to population ratio in Saskatchewan if further efforts are demanded of the community nurse. It would also be unfair to expect that the present level of knowledge and training would be fully adequate. The community nurse who is to intervene effectively in problem pregnancy and child care situations will need further training in antenatal care, family planning, early childhood development and simple genetics. Given adequate training and support, the caliber of community health nurses is equal to the task required and can be regarded as an extension of their traditional involvement with mothers and small children in the promotion of public health.

Patterns of nursing and medical activity may need modification to ensure that effective prevention is carried out. Women receiving

antenatal care traditionally attend their family physicians or a specialist obstetrician. When this is done regularly there is often no problem, or none that cannot be anticipated. Problems often arise when medical supervision is not maintained. The involvement of other community health workers to a far greater degree than there is practiced at present may be required to reach all members of the population, and particularly to those who need the most help. Public health nurses, social workers, visiting homemakers, and interested and informed members of the public all have a part to play, and innovative patterns of care of individuals and cooperation between professionals may well be required for the most effective service.

d) Prevention as a Social Services Activity

Departments of Social Welfare everywhere are hard pressed, short of funds, and faced with nearly impossible tasks. Many of those who need their services are lacking in education, short of money, and suffering from illness or handicap. Attempts to prevent various social catastrophies by action before they occur have been made, but usually on a very small scale. In Saskatchewan for example the concept of a guaranteed family income has been considered, and some provisions are available for augmenting the incomes of hard pressed families.

The area of potentially preventable retardation and developmental handicap might be one in which preventive social services could be most effective. Studies are available to show that if the pregnant teenager is given adequate support, she could be taken through her pregnancy and produce a healthy baby in the great majority of instances.

The result of intervention in such problems appear to be equally good whether infants are retained by their young mothers or adopted. An organized program of medical and social intervention is required to prevent the medical and social consequences of unwanted pregnancies in conditions of social disadvantage. It should be the type of program in which selective termination of pregnancy and the promotion of effective family planning may play a big part. The manner in which such programs should be carried out is very controversial, and the results of intervention may not become apparent for a considerable period. Many procedures might be tried. In France, for example, where in recent years there has been a remarkable improvement in antenatal and perinatal care, payments have sometimes been made to needy families simply to ensure that they attended particular services such an antenatal clinic. Any methods which improve the health of parents to be, expectant mothers, and babies and small children are likely to contribute to a reduction of the conditions in which mental retardation, brain damage, and developmental disability arise. Adequate money, some of which is actually spent on adequate nutrition, suitable housing, and support in times of crisis are all factors in which a social welfare department can properly concern itself, and in which long term economies can probably be made if resources are brought to bear upon the problem before catastrophies occur.

e) <u>The Role of the Department of Education</u>

The responsibilities of departments of education usually begin at

the age which children go to school. For many children however, this is far too late. Whatever the problems may be, at the age of 5 or 6 it is usually well established, and any measures taken to deal with it are more amelioration than prevention. The Department of Special Education in Saskatchewan has shown a commendable interest in such problems, and has a policy of trying to avoid excluding any child within the educational system. Whether the Department of Education, as presently organized, could be expected to accept responsibility for early intervention programs in pre-school children, is open to debate. The development of a capacity to provide pre-school education, however, might be something with which the Department of Education could concern itself. The present over supply of trainees for the teaching profession might provide recruits for a dimension of education which requires development.

The issue of public knowledge of human reproduction and of the capacity of ordinary people to take an important part in their own destiny and the destiny of their children, is surely something which deserves attention in the world of education. Our committee felt that some of this knowledge could well be part of the education of adolescents, who are frequently very interested to hear factual information about sexual matters, family life, and biology in general. Some of the information now available would also be of great interest to prospective parents, and suitable material, in conjunction with health departments, for courses in community colleges. Departments of special education and and continuing education appear to have a real role to play in attempting

to improve developmental handicap and to help the public understand the circumstances in which it may occur.

2. Prevention Institute:

The suggestion that there should be an institute in the Province of Saskatchewan devoted to considering the problems of prevention of mental retardation and developmental disability has arisen from the Committee on Prevention formed by the Saskatchewan Association of Mental Retardation. At a combined meeting with this committee, our committee felt that there was much merit in this suggestion and a combined committee of the Saskatchewan Association of Mental Retardation and the provincial government, to study the implementation of the project, has met and submitted a report. The principle of an institute for prevention has been accepted. Plans for implementation of this institute are under consideration at the present time.

The proposed prevention institute has aroused mixed feelings. Some organizations, including those in academic circles, and those concerned with professional education such as the Continuing Medical and Nursing Education Program have expressed anxieties about duplication of function and competition for scarce funds. Anxieties have also been expressed by government departments, such as the Department of Health, who often have very constrained financial resources in attempting to carry out programs with objectives similar to those of the Prevention Committee.

Our committee felt, with some reservations, that these very objections might, in a sense, be an indication that a prevention institute

ought to exist. As one of its proponents pointed out, the objective of the prevention institute is not to compete with any other organization interested in the same subject, but to try and further its objectives, and yet to retain sufficient autonomy to keep the various issues alive. The Prevention Institute has shown that it is a project which may well be able to raise financial support from the voluntary sector which would not be available to government department. They would also be able to bring forward issues which the University or government departments might not wish to raise because of financial implications or for any other reasons. An institute for prevention which had a degree of independence from institutions of government or academic life could well speak directly to the public, and do something to capture their interest in the prevention of developmental handicap. It might provide an ongoing forum in which the problems and issues of prevention could receive continual consideration until effective action occurred.

Members of our committee felt there was reason to support the general idea of the prevention institute, and to welcome the initiative which had brought the concept into being. The major reservation was that the development of an institute for prevention was, in itself, no substitute for the action necessary by government departments, educational institutions and voluntary agencies in developing a broad and effective approach to prevention. A prevention institute could well question the reasons for an incomplete prevention program which was technically possible, such as the 10% of potential mothers

who are susceptible to the Rubella virus. Although the solution to this particular problem would be a Department of Health responsibility, such an institute would play an important role in promoting sufficient public interest in the problem to developing effective response. Many other examples could be quoted. The effectiveness of the institute would depend very largely on the quality of individuals involved with it. There is little doubt that talent exists in Saskatchewan to make such an institute an effective instrument of change provided general interest in the problem of prevention is maintained, and the organizational problems are solved.

The province of Saskatchewan has a long tradition of addressing itself effectively to various problems of human health and welfare, and the dovetailing of voluntary, professional and governmental involvement in such activities is part of the tradition. Many different patterns of action have developed, and some of them have been very effective. Examples of organizational patterns in the past in Saskatchewan have been the Anti-Tuberculosis League, the Cancer Commission, Committee on Aging and Long Term Illness, the Advisory Planning Committee on Medical Care, and the Council for Exceptional Children. There has been a substantial Saskatchewan component in many federal commissions such as the Commission on Emotional and Learning Disorders in Children. All these activities have played their part, some on a short term basis, some on a continuing level of program activity. Some aspects of the problem of developmental handicap have received consideration in the past. There have been associations

for the mentally retarded, parents groups for the physically handicapped and cerebral palsy, and a variety of societies, programs and evidences of interest in different aspects of the problem of developmental handicap. There has not yet, anywhere, been a concerted effort to look at the problem of developmental handicap as a whole and to promote programs that will reduce it. It is an enormous task, but the means to accomplish it are becoming available. Saskatchewan could well have the means to launch such a program, and the institute for the prevention of mental retardation and developmental handicap could possibly be a major influence in bringing such programs about.

APPENDIX A

PRECIS OF MEETINGS

Eleven meetings were held, with guest experts invited to each meeting to discuss various aspects of mental retardation and developmental disabilities. A summary follows:

MEETING: I

THEME: Hereditary Disease and Genetic Counselling

GUEST PARTICIPANTS:

O. E. Laxdal, M.D., F.R.C.P. (C)
Professor and Director
Division of Continuing Medical Education
University of Saskatchewan, Saskatoon

E. L. Ives, M.D., F.R.C.P. (C)
Professor of Pediatrics and
Director of Medical Genetics
University of Saskatchewan, Saskatoon

DISCUSSION:

1. Clarification of information about genetic and chromosomal abnormalities.
2. Consideration of general purposes of the Committee.
3. The affect this Committee would have in view of known problems in obtaining effective coordination of government departments with different priorities and objectives.
4. Decision made to place emphasis on primary prevention related to overall cost of care and consideration of dissemination of pertinent information to the public and allied health science professions.

MEETING: II

THEME: Antenatal and Perinatal Care

GUEST PARTICIPANTS:

T. B. MacLachlan, M.D., F.R.C.S. (C)
Professor and Head
Department of Obstetrics and Gynecology
University of Saskatchewan, Saskatoon

T. Ward, M.D., F.R.C.P. (C)
Director of Neonatal Unit
University Hospital
Saskatoon, Saskatchewan

DISCUSSION:

1. Opportunities for improving the outlook for mothers who experience problems during pregnancy and the importance of adequate technical resources for diagnosis and management of antenatal conditions and newborn care.

2. Technical deficiencies in Saskatchewan Services.

3. Social factors relating to high risk pregnancy and low income.

4. "At risk" inventories as shown in Appendix G, and the benefits of regionalization of reproductive and perinatal care.

5. Cost of adequate perinatal services in Regina and Saskatoon with the Committee being informed that a rough estimate of one million dollars was considered necessary to develop adequate antenatal and perinatal services in both cities. This figure was contrasted with the fact that this figure may be compared to an estimated lifetime cost of a single case of mental retardation.

MEETING: III

THEME: Social Issues In Prevention

GUEST PARTICIPANTS:

Mr. Fred Harshman
Coordinator
National Institute of Mental Retardation
Western Region

Dr. Robert Sanche
President
Saskatchewan Association of Mental Retardation

Miss Sandra Stewart
Information Officer
Saskatchewan Association of Mental Retardation

DISCUSSION:

1. Role of volunteer agencies who have great interest and proven effectiveness in bringing preventive problems to public attention.

2. Outline of S.A.M.R. proposals for an Institute for Prevention of Handicapping Conditions was presented.

MEETING: IV

THEME: Acquired Retardation; Infections and Toxic Agents

GUEST PARTICIPANTS: Dr. Clive Dennis
Prairie Institute of Environmental Health
Regina, Saskatchewan

Dr. George Davidson
Provincial Epidemiologist
Department of Health
Regina, Saskatchewan

DISCUSSION: 1. The effect of environmental pollutants on mental retardation and the relationship between developmental disability, mercury pollution and the use of agricultural spray.

2. Emphasis was placed on rubella, a preventable cause of severe retardation.

MEETING: V

THEME: Early Intervention as a Means of Prevention

GUEST PARTICIPANTS: Mr. Eigel Jensen
Mrs. Wilma Clark
Alvin Buckwold Centre
Saskatoon, Saskatchewan

M. D. Morrison, M.D., F.R.C.S. (C)
Associate Professor
Department of E.N.T.
University of Saskatchewan, Saskatoon

DISCUSSION: 1. Problems and opportunities of early intervention as a preventive measure, and the fact that this is still in the early stages of development.

2. Deafness as a component of mental retardation.

3. Problems of early screening and of utilizing results. The Committee was told that perhaps 10% of all children labelled mentally retarded were of normal mentality but born into an environment sufficiently deficient to "cause" mental retardation.

MEETING: VI

THEME: Economic Implications and Future Projection

GUEST PARTICIPANTS: Mr. R. Baxter
Director of Mental Retardation Division
Department of Social Services
Regina, Saskatchewan

Mr. Fred Gattinger
Deputy Director
Valley View Centre
Moose Jaw, Saskatchewan

DISCUSSION: 1. Future projections of the problems of mental retardation and economic resources needed to deal with it. Institutional costs for retarded in Saskatchewan of $12 million per annum consume twice as much money as whole regional health services.

2. The potential of effective strategies in prevention and alleviation compared to institutional care.

3. The relationship between cause and effect in mental retardation, although often not fully known, a medical or biological cause can be detected in 30-60%.

4. The need for an informed population of parents which could be made possible through use of public funds in educating said public through appropriate information programs.

MEETING: VII

THEME: Review of other Professional Education Programs

GUEST PARTICIPANTS: Dr. F. Baker
Chairman, Perinatal Advisory Committee
Saskatoon, Saskatchewan

DISCUSSION: 1. Consideration of reports from Committee members who had attended various meetings related to mental retardation and developmental disabilities.

2. The lack of comprehensive programs geared toward prevention of mental retardation and the fact that Canada and Saskatchewan are as advanced to the same degree as the U.S.

3. Report of recent improvement in perinatal programs in Saskatchewan and review of results in reduction of brain damage and improvement in the quality of survivors being obtained in areas where there are highly developed perinatal programs.

4. Changes in other countries, particularly Sweden and France, which have resulted in recent improvements.

MEETING: VIII

THEME: Combined meeting with Saskatchewan Association of Mental Retardation

GUEST PARTICIPANTS: Members of the Saskatchewan Association of Mental Retardation
Dr. Robert Sanche, President
Dr. T. Ward, Director of Neonatology, Saskatoon
Dr. T. Russell, Director, Youth Services, Regina
Mr. John Dolan, Executive Director, S.A.M.R., Saskatoon
Mr. John Crawford, Department of Social and Preventive Medicine, Saskatoon

DISCUSSION: 1. Feasibility of establishing a Prevention Institute as an innovative means of promoting effective prevention in the Province of Saskatchewan.

MEETING: IX

THEME: Review of Committee Proceedings

DISCUSSION: 1. Presentation and discussion of tentative draft on the Prevention of Mental Retardation and consideration of the relationship between medical and social aspects.

2. Need for improvement in public knowledge about reproduction, heredity, availability of services, nutrition and responsible parenthood.

MEETING: X

THEME: REVIEW OF DRAFT PROCEEDINGS

DISCUSSION: As above

MEETING: XI

THEME: Summation of Proceedings

DISCUSSION: 1. Consideration of the desirability for establishment of a Preventive Institute.

2. Decision that the need for support of existing programs was judged to be of the highest priority.

APPENDIX B

Subdivision and Classification of Persons with an Intelligence Quotient below 70

Intelligence	Quotient Classification
150+	genius
136 - 150	gifted
115 - 135	superior
85 - 115	normal
70 - 85	slow learner
0 - 70	retarded 3% of population

Classification of Retarded based on I.Q.

	Total	50-70	30-50	0-30
Per Million population	30,000	24,000	4,500	1,500
In Saskatchewan	27,000	22,000	4,250	1,250
Classification		educable	trainable	severe
Old Terminology		moron	imbecile	profound idiot

APPENDIX C

DEFINITIONS

Cerebral Palsy: the commonest cause of crippling disease among children, is actually a serious of conditions in which the common factor is brain damage leading to impaired mobility. Approximately 50% of these children have some degree of mental retardation. Several important causes of cerebral palsy, such as those due to the rhesus factor or prematurity, can now often be prevented by appropriate treatment.

Congenital Amputations and Limb Deficiency: these conditions are usually associated with mental retardation. Their possible relationship to some environmental factors were shown 15 years ago when the numbers increased in countries in which their mothers had given Thalidomide as a sedative.

First Degree Relatives: parents and siblings.

Minimal Brain Damage: the rather unsatisfactory term "minimal brain damage" includes a great many disorders of a rather troublesome and subtle nature which give rise to difficulties in education. The relationship of such conditions to structural and chemical disorders of the brain is a controversial issue, but evidence is accumulating that optimum treatment for developmental problems, such as prematurity, may reduce the incidence of educational problems in later life. The term "minimal brain damage" includes the following categories of clinical and educational problems: Dyslexia, perceptual disorder, "clumsy child syndrome"

hyperactivity, visual imperception, and auditory imperception. None are very accurate descriptions but all are facets of a large problem.

Muscular Dystrophies and Atrophies: Muscular dystrophies and atrophies form a group of hereditary disorders which may be of great severity. The most severe form, Pseudo-hypertrophic Muscular Dystrophy, is confined to boys, associated with invariable death in adolescence or early adult life, and transmitted by female carriers. The carrier may sometimes be identified by a blood test for a serum enzyme.

Myelomeningocoele and Hydrocephalus: this is one of the more common severe congenital malformations, producing children with multiple handicaps including paralysis of the legs, bladder and bowel. Special services are required to help these children, who may be of normal intelligence or may have mental retardation associated with hydrocephalus. Recent diagnostic advances indicate that such conditions may be identified in the prenatal period.

Other Congenital Abnormalities: Congenital abnormalities not associated with retardation, disorders of brain function, crippling disease or sensory defects form a large part of the work of the pediatric departments. Many such defects, particularly those associated with the gastrointestinal tract, the heart, and such conditions as cleft palate, are amenable to surgical correction. Programs which consider the prevention of mental retardation and developmental abnormalities as a whole, may eventually lead to some reduction in

congenital abnormalities in other systems as well as the brain.

Sensory Disorders: Disorders of the middle ear or external eye, which once cause a considerable amount of deafness or blindness, are now usually amenable to treatment. Permanent disorders of sight or hearing in early life usually have a developmental origin. An important example is the association of cataracts in the eye or nerve deafness with prenatal infection by the rubella virus. Sensory disorders can contribute to mental retardation in two ways. They may be associated with a disorder of brain structure and function, and be part of a picture of severe disability. Defects of sight or hearing, however, may be associated with a potentially normal brain, but contribute to apparent retardation if the sensory defect is not recognized and corrected as far as possible.

Second Degree Relatives: grandparents, grandchildren, uncles, aunts, first cousins.

APPENDIX D

Current Information Sources on Prevention of Mental Retardation and Developmental Disability

1

Begab, M. J. Mental Retardation: Shall We Prevent It? American Journal of Mental Deficiency, March, 1974

2

Fotheringham, John & Mary Morrison. Prevention of Mental Retardation. National Institute of Mental Retardation in Canada, 1976 *

3

Hayword, H. K. and William R. Pupke, Carl F. Calkins. Prevention of Developmental Disabilities in the State of Tennessee

4

Milunsky, Aubrey. Prevention of Genetic Disease and Mental Retardation. W. B. Saunders Company/Philadelphia/London/Toronto Publisher

5

Wynn, Arthur and Margaret. Prevention of Handicap of Perinatal Origin. Council for Children's Welfare, England, 1974

6

Wynn, Arthur and Margaret. The Protection of Maternity in Infancy.

7

Etiology of Mental Sub-normality (Study in Scotland)

8

Preventing Retardation: More Can be Done. Report to the Congress of the U.S.A., The Comptroller General of the U.S.A., October, 1977.

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* One of the most valuable, succinct documents. This communication covers the subject thoroughly but briefly, and is written for members of the general public who have a special interest in the problem, but with sufficient depth to meet the needs of professionals in the field.

APPENDIX E

The Special Problem of Down's Syndrome

There are three forms:

1) Due to Trisomy 21 (3 chromosomes number 21 instead of the normal two)	95% of all Down's Syndrome
2) Translocation	Rare but important as it may recur in the same family
3) Mosaic, or partial	Appears to be very rare

These comments apply to the <u>common form, Trisomy 21</u>:

1) This is probably the commonest single cause of mental retardation;

2) About half of all these children are born to women over the age of 35, who normally bear about 13% of children;

3) It is possible to identify the condition in the unborn child by amniocentesis and chromosome study of amniotic fluid; (This is now done for many women bearing children in the later child bearing years)

4) This procedure is possible sufficiently early in gestation to permit safe termination of the pregnancy;

5) Termination of pregnancy is necessary to 'prevent' the condition;

6) Down's Syndrome children are usually moderately retarded but with adequate home support and educational services, are among the most rewarding of mentally handicapped children to raise;

7) The ethical problems require clear understanding by the public.

APPENDIX F

NEURAL TUBE DEFECTS

The neural tube is the cavity inside the brain and spinal cord. Abnormalities in the development of the tube are associated with serious developmental defects, the main two of which are:

1. Anencephaly or absence of the cerebral hemispheres, which is incompatible with prolonged life.

2. Myelomeningocoele or open spina bifida, which is associated with paralysis of the legs, bladder and bowel, and frequently complicated by hydrocephalus. Myelomeningocoele is variable in degree, sometimes compatible with prolonged or normal life span and normal intelligence, but requires an intense concentration of special services to achieve satisfactory function.

These defects occur somewhat more commonly in families where a previous case has occurred. Testing has usually been restricted to mothers who have previously born such a child, however most neural tube defects occur among the pregnancies of healthy women with no family history of the condition.

Neural tube defects can be diagnosed before birth by the identification of a substance called alpha feto-protein in the amniotic fluid, which has led to termination of pregnancies in which myelomeningocoele has been confirmed.

Current research has indicated that the presence of alpha feto-protein

in the blood of the mother may be an indication that she is carrying a fetus with a neural tube defect, which may lead to a screening test which could be used in all pregnancies, as a guide to those needing amniocentesis, however, the question of the extent to which such testing and subsequent termination of pregnancy should be used to reduce the incidence of a serious congenital defect must be answered.

APPENDIX G

Antepartum Fetal Risk Score

Modification of score devised by J. W. Goodwin, J. T. Dunne and B. W. Thomas

CATEGORY I
Baseline Data (Pre-pregnancy)

Age 15 or under 1
Age 35 + ...1

Age 40 + ...2
Para 0 1
Para 5 + ...2
Interval 2 years 1
Isolation: 50+ miles from medical care 2

Weight 100 lbs. (45 kg) 1
Weight 200 lbs. + (90 kg) 2
Diabetes Class A 1
Class B, C, D, ...2
Class F, R, ...3
Chronic renal disease 1
Chronic renal disease with diminished renal function 3
Pre-existing hypertension
140/90 1

160/110 2
Interpregnancy cardiac failure 2

Rh isoimmunized mother (1:8 AHG +)
with homozygous husband 2
with previously affected infant (regardless of outcome) 3
Score (circle one) 0 1 2 3

Reproductive History
Abortion, spontaneous
Abortion, Therapeutic
Pelvic infection, post abortal or postpartum

Fetal death
Neonatal death
Surviving premature infant
Surviving infant, low birth weight for dates

Antepartum hemorrhage
Toxemia
Difficult Midforceps
Cesarean section
Hysterotomy
Myomectomy
Major congenital anomaly
Cervical incompetence
Large infant: 10 lbs. + (4.5 kg)
Malpresentation

One instance of above 1
Two or more instances of the above (in one or more pregnancies.2

CATEGORY II
Present Pregnancy
Bleeding early (20 wk.)
Alone 1
With pain 2
Bleeding late (20 wk.)
Ceased 1
Continues 2
With pain 3
With hypotension 3
Asymptomatic bacteriuria 1
Toxemia grade 1 1
Toxemia grade 11 3
Eclampsia 3

No antepartum care 2
Less than 3 visits 1
Heart disease: AHA functional Class III or IV 2

Anemia
10 gm or less 1
10 gm after 36 wk 2
8 gm or less 2
Megaloblastic anemia 2

Spontaneous premature rupture of membranes 1
With latent period 24 hours 2

Specific infections
Untreated syphilis 2
Toxoplasmosis 2

APPENDIX G (continued)

Hydramnios (single fetus) 3
Multiple pregnancy 2
Gestational diabetes
Diagnosis before 36 wk 1
Diagnosis after 36 wk 2
Decreasing insulin requirement
(50% + reduction in 48 hr 3
Maternal acidosis 3
Maternal pyrexia (39C+) 1
Maternal pyrexia + FHR 160 2
Rising Rh antibody titre (2 Tube +) 2

Hepatitis 1
Vaccination during pregnancy 1
Rubella titre rising significantly
6 wk 3
12 wk 2
12 wk 1

Inhalation anesthesia (emergency)1
Abdominal operation 2
Cervical suture (Cerclage) 3
Pelvic Irradiation diagnostic 12wk1

Score (circle one) 0 1 2 3

CATEGORY III

Gestational Age Achieved
28 weeks or under 4
32 weeks or under 3
35 weeks or under 2

37 weeks or under 1
42 weeks or over 1
43 weeks or over 2

Score (circle one) 0 1 2 3 4

APPENDIX H

The Problem of Rubella

1) The Rubella Virus causes an illness in children and adults which is nearly always trivial.

2) Rubella is a serious condition if it occurs in pregnancy. If a woman in the first three months of pregnancy contracts Rubella, it may affect her unborn child very seriously, damaging the inner ear, the eye, the brain, or the heart. Children damaged by Rubella Virus often have severe multiple handicaps.

3) This severe multiple handicap can be prevented by ensuring that women have antibodies to the Rubella virus before they become pregnant.

4) Rubella antibodies may be generated by 'natural' infection with Rubella virus in early live, or by immunization with a vaccine.

5) Natural infection usually gives life-long immunity.

6) The only vaccine at present available is a live-attenuated vaccine.

7) The effectiveness of the vaccine is somewhat doubtful. Teenage girls given Rubella vaccine are not always adequately protected through their child bearing years.

8) The vaccine, being a live vaccine, may have the same effects on the unborn child as a 'natural' infection. It must not, therefore, be given to women who are pregnant.

9) Susceptibility to Rubella can be determined on blood samples. Tests are being done in premarital blood samples in Saskatchewan.

10) Results of these tests show that about 20% of women do not have adequate Rubella antibodies.

11) Efforts directed to immunizing such susceptible individuals have been relatively ineffective, although vaccine is available.

12) Rubella epidemics occur periodically, usually at 10 to 15 year intervals.

If one occurred in Saskatchewan, the number of people affected might be limited and disaster to unborn children might be few in numbers. The intensity of damage to the fetus, however, could well lead to life-long care for these children.

APPENDIX I

Management of High Risk Pregnancy and

Intensive Care

Babson, Benson, Pernoll, Benda

C. V. Mosby Company

1. Improve the timing, quality and quantity of pre-conceptual care
2. Encourage earlier pre-natal care
3. Identify high risk patients early
4. Permit abortion for unwanted pregnancy
5. Offer genetic counselling for families where known defects occur
6. Limit smoking and alcohol in pregnancy
7. Improve obstetric care through regionalization and a team approach to problems
8. Expand regional centres to provide complete obstetric and perinatal services.
9. Implement effective care to under-privileged persons
10. Diagnose twins early to improve management
11. Supervise adequacy of diet for pregnant women
12. Provide effective home help situations when domestic difficulties exist
13. Treat genital infections adequately
14. Insure correct management of hemorrhage in pregnancy
15. Avoid ill timed intervention and test for fetal maturity before intervening
16. Administer Rh D (immunglobilin) to rhesus negative mothers after birth or miscarriage

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Special Note: The members of the committee would probably modify this list by giving prevention of Rubella a high priority. Some of the members of the committee have reservations about a general endorsement of abortion simply because a pregnancy was unwanted.